

The Bloodline

Hemophilia of Iowa, Inc.

DANCE
like there's nobody watching
LOVE
like you'll never get hurt
SING
like there's nobody listening!

Volume 24 • Issue 3

Fall 2010



From the President . . .

By Kari Atkinson

With the 4th of July holiday behind us, I hope that everyone has been enjoying the summer break and that families are able to spend some quality time together. Summer time for HOI is always busy with events. Thank you to all members who have made the choice to join our organization in 2010 and to those of you who have attended our events. You have helped make this summer a fun and successful season. There is still plenty of time to become a member and join us for future events. If anyone has any questions about any of these upcoming events, please do not hesitate to contact me at 319-721-3964.

Congratulations to all of the graduates, if it is preschool, kindergarten, elementary, middle school, high school or college, we wish all of you the best.

Please continue to check out this newsletter as well as future issues for upcoming event information. As you may have noticed, we are working toward online registrations for these events; and we know that this comes with new challenges and growing pains. So, bear with us while we work out the kinks and make the system as user friendly as we possibly can.

As we get closer to our 2010 Annual Education Weekend on September 17-19, would you consider becoming a Board member? It is a very rewarding position and you get to know so many people while working together on committees and at events. Please see my open letter to members in this issue of the BloodLine for more details.

Remember it is biking and skateboarding time; take the extra minute and put on that helmet. Safety First!!



EDITOR:

Nancy Patrilla

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Mom's Day Out

The First Step group held a Mom's Day Out on April 17, 2010, in Des Moines. The day was filled with pampering, education and fellowship. Moms were treated to a nice breakfast, their choice of a manicure, pedicure or massage at LaJames in Des Moines. We then had a very nice lunch with a motivational speaker who has 12 children. That is not a typo; the number really is 12. Special thanks to the sponsors of the event, who were Axelacare, Baxter, Bayer, Novo Nordisk, Talecris and Mid West Cornerstone.

Upcoming First Step Event: Dad's Day Out—Date is TBD.



"Nobody can go back and start a new beginning, but anyone can start today and make a new ending."

*Hemophilia of Iowa
does not endorse
any specific industry
organization, product,
or service.*



Upcoming Fall Family Event "Day At The Pumpkin Patch" to be determined

More details will be sent to all of you with children aged 0-8 who have bleeding disorders.

If anyone is new to receiving this BloodLine and wonders what First Step is, it is a program offered through the National Hemophilia Foundation; and it is designed to provide education and support for families with children aged 0-8 who have a bleeding disorder. If you have a child that age, we would love to hear from you and include you in our fun outings. Please feel free to contact either Kari Atkinson, HOI President and Parent Coordinator, or Tami and Karla at the HTC. We would be more than happy to help you and your family in any way that we can.

Resources for Insurance Coverage and Questions

COBRA (Information on how you can continue insurance coverage after you lose current coverage)
www.dol.gov/dol/topic/health-plans/cobra.htm

PSI (A great resource for help with insurance issues - ranging from helping find insurance coverage to helping fund some financial needs relating to insurance premiums and medical treatment)
www.uneedpsi.org

A.C.C.E.S.S. (A wonderful resource for any question on insurance and legal issues)
www.uneedpsi.org/CMS400Min/about/index.aspx?id=50



2010 Adult Retreat

By Brian Unruh

This year's adult retreat was held at the Iowa Speedway in Newton, Iowa, on May 15-16. If you have never felt the rush and force of going 140 mph in a race car, you missed your chance. The group of adults who gathered together for fun, learning, and socializing experienced this rare event. Our group gathered together on Saturday afternoon and enjoyed meeting the drivers and riding along wearing full gear.

After the racing was finished, we took a tour of the facilities, watched a 60 lap race, and ate supper on the infield of the racetrack. After supper, we took time to remember Jim Brown, who was instrumental in the event taking place. We challenged ourselves to carry out his message of "I Can" in our lives.

This was a time that not many of us will forget any time soon!

Get Involved!

Hemophilia of Iowa is expanding our successful letter writing campaign. Could you help by bringing at least five (5) names and addresses to the annual meeting that you would be willing to share with the fundraising committee? We will then send those individuals a letter from Hemophilia of Iowa during our letter writing campaign. (Your name will not be mentioned in the letter without your express permission.) This is an easy and productive way you can be involved in one of the fundraisers for HOI. We look forward to another successful campaign this year with your help!

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How Will Healthcare Reform Affect YOU?

Most people still wonder exactly how healthcare reform will be enacted, what impact it will have on them, and on our community. The latest edition of *PEN's Insurance Pulse*, a newsletter published by LA Kelley Communications and designed specifically for families and patients affected by bleeding disorders, answers many questions people are asking about the changing landscape of healthcare insurance.

As you likely know by now, the bill that President Obama signed into law in March eliminates lifetime caps and prohibits denial of coverage due to pre-existing conditions, including hemophilia. The primary focus of the law is on insurance reform, and this issue of *Pulse* covers many topics of concern to our community, including the risks associated with allowing insurance to lapse, payment assistance services

available to the unemployed, changes in insurance coverage for young adults, and more.

The new issue of *Pulse* offers several points of view on what the Patient Protection and Affordable Care Act means to different members of the bleeding disorder community. Expert sources and guest authors offer their assessments and predictions on how healthcare reform will affect us directly. Graphics and statistics provide readers with additional insights. And Laurie's cover story provides an excellent overview of the impact of this landmark legislation.

"Many of the new reform mandates, should they stay, will not go into effect immediately; some will take years," Laurie wrote in a cover letter to *Pulse* readers. "You'll need to stay informed on healthcare insurance issues so you know what's changing, what's not, and how any changes will affect our community and your own healthcare. As a parent of a child with hemophilia, or a person with hemophilia, you'll always need to learn about insurance and reimbursement to stay current and to understand the nuances of your coverage."

PEN's Insurance Pulse is a free publication. If you would like a copy of *Pulse*, contact LA Kelley Communications at 800-249-7977 or email her at info@kelleycom.com.

New Regulations Released Affecting Health Insurance Market

On Tuesday, June 22, 2010, the Obama administration published interim final regulations implementing several of the private insurance market reforms that will become effective on or after September 23, 2010. The regulations are intended to provide guidance on the private insurance market reforms set forth in the Patient Protection and Affordable Care Act (PPACA), as modified by the Health Care and Education Reconciliation Act of 2010 (HCERA), regarding lifetime and annual limits, pre-existing condition exclusions, rescissions and other patient protections. These interim final regulations will be open for comment until 8/27/10

Source: www.hemophilia.org website (NHF)

Update: Regulations Issued for Young Adult Coverage

Regulators have begun to define the young adult coverage provision and released interim regulations recently. This provision will also go into effect September 23, 2010. The interim regulations can be found at: http://www.hhs.gov/ociio/regulations/pr_a_omnibus_final.pdf

Highlights of the regulations include:

- Dependency can no longer be defined by student status, age, financial dependence, or residing with parents
- This impacts all healthcare plans and should allow all adults until age 26 to gain health insurance under their parents' plan
- If the young adult can gain employer-based coverage, they may be denied coverage under parents' plan

For additional information on the dependent coverage (young adult coverage), please go to the website listed below and click on the following links: [Dependent Coverage Fact Sheet](#) and [FAQ - Dependent Coverage](#)

Source: <http://hemophiliafed.org>



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Scholarship Thank You

By Ben Meyer

My name is Ben Meyer. I recently graduated from Iowa State University with a Bachelors of Science degree in Industrial Technology. I would like to thank you for the scholarships that I received last fall. They were used to help fund my senior year at school.

This past August I underwent surgery to repair my ankle. Because of this surgery, I was unable to work all last fall to help pay for school. The scholarships greatly helped reduce the burden of tuition and books. The surgery went well, and I am still in the strengthening and rehabilitation phase. I hope to be near 100% by next spring.

I would also like to thank you for all the financial help that you have given me all through college. I recently accepted a position with Halliburton as a field engineer working at well sites preparing the ground for extraction of natural gas. I will start orientation and training there the middle of June and will be located in Bossier City, Louisiana.

Again, I would like to thank you for all your help and support. Your kindness and generosity have greatly helped me throughout college. I will take what I have learned the last few years in school and apply it to this position and everyday life. I would not be where I am today without the help of Hemophilia of Iowa and all the people who support it. Thanks.



Ricky and Rachelle Nolan and their children, Cade, Gavin, Tyler and Ava.

Board Member Profile

By Rachelle Nolan

It is an honor to have been selected to serve on the Hemophilia of Iowa Board of Directors and to have been appointed Secretary of this organization. My family and I have enjoyed participating in many events, and I look forward to helping our community in any way possible in the future. My husband, Ricky, and I have four children: Cade (9), Gavin (6, with Severe Hemophilia A), Tyler (4), and Ava (3). We reside in Jesup, Iowa.

I am a Licensed Practical Nurse (LPN) at Partners in Obstetrics and Gynecology in Waterloo, Iowa. I attended Kaplan University for my nursing degree. Previously I worked at Covenant Medical Center in Labor

and Delivery as an O.B. technician. My husband does Customer Relations for Bossard Industrial Products in Cedar Falls, Iowa, and has been there for 14 years. He is also a volleyball coach at Waterloo East High School.

We are a busy family who enjoys athletics, volunteering, camping and spending time with family and friends. I also enjoy scrapbooking and reading. Through the bleeding disorders community we have developed many cherished friendships and gained the knowledge and support we need to raise a happy and active family. Though our hands may be full, so are our hearts. Thank you for this opportunity to contribute to this exceptional community.

Did you know . . .

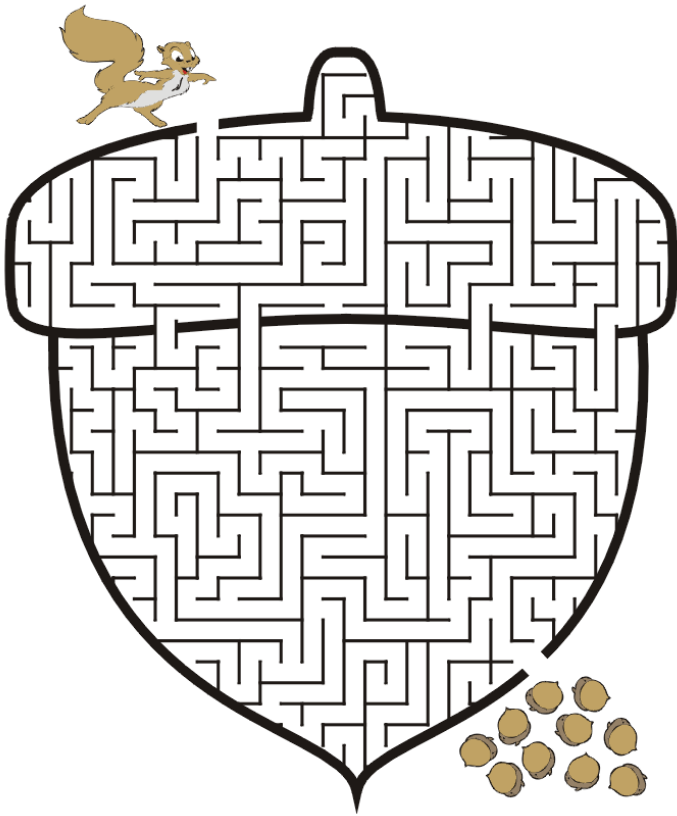
that the membership application, payment of your dues and/or making a donation can now be done online?

Please visit the website at

www.hemophiliaofiowa.com

for more details.

Help the squirrel through the maze to find its acorns.



World's First Book on Inhibitors almost done

The finishing touches are being done on the world's first book on inhibitors: *Managing Your Child's Inhibitor: A Practical Guide for Parents*.

Topics include in-depth chapters on inhibitor formation, treatment of acute bleeds, ITI, pain management and surgery. Also included is a whole section on the day-to-day concerns and life with inhibitors. Information has been researched and documented; and the text is interspersed with quotations from 40 parents and patients who volunteered to share their life with inhibitors.

Preorders are being taken by LAKelleyCommunications, Inc., so they can have an accurate production run. If you'd like to place an order, please contact them at once. The book is available for \$18.95 and your order will be added to the production run. There will only be limited quantities available after the first run, so please place your order today to ensure availability!

You can call them at 800-249-7977 or e-mail them at info@kelleycom.com.

The Oldest American with an Inhibitor

By Kerry Fatula

Hemophilia and inhibitors are complex conditions, and stories of misdiagnosis and mismanagement are familiar. But fortunately, such stories are far less common than they once were.

Perry Stone, 87, has mild to moderate hemophilia A. And he thinks he may be the oldest living American known to have an inhibitor. Recently, Perry told me the story of how he handled "mysterious bleeding" until the diagnosis was finally made.

Perry was born in 1923 in Chicago, to immigrant parents. His Russian mother and Romanian father had no known family history of hemophilia, and Perry was the only one of their five children to experience mysterious, prolonged bleeding. In his early childhood, Perry commonly had nosebleeds that came unexpectedly and wouldn't stop. Doctors had no explanation, and cold compresses were the only treatment. Perry can recall no joint bleeds during his early years. He was active in school, playing baseball and basketball with no difficulty aside from the nosebleeds.

When he finished school, Perry joined the army and served more than three years during World War II. He continued to suffer from nosebleeds, but the military doctors could find no explanation. In 1943 Perry married, and he and his wife Betty had two daughters. Returning to civilian life in 1946, he began working in the insurance industry.

For most of his life, Perry's undiagnosed hemophilia had presented few problems, but as he got older, things changed. In 1966, at age 43, Perry began to experience spontaneous bleeding into the thigh muscles of both legs. The bleeding kept him from working and led to a week-long hospital stay. Doctors still had no explanation and did not test Perry for hemophilia. Instead, they treated Perry with vitamin K injections. When the bleeding subsided two weeks later, doctors mistakenly credited vitamin K as an effective treatment.

In 1974, at age 51, Perry suffered a heart attack. After receiving an arteriogram, the arm used to insert the intravenous catheter developed a baseball-sized hematoma that wouldn't heal. Yet doctors still ran no tests to look for a bleeding disorder.

A year later, when Perry had a tooth extracted and bled for nearly a month, his physician suspected von Willebrand disease, and finally ordered a blood test. When the lab results came back, the diagnosis was hemophilia A.

Perry was lucky to finally have received a diagnosis, because in 1979 he needed all of his teeth extracted. The

(Continued on page 10)

DONATIONS

January 1-June 15, 2010

\$20,000+

Novo Nordisk Inc.

\$17,000 - \$19,999

Baxter HealthCare Corporation

\$14,000 - \$16,999

Camp Superfly (Baxter)
Bayer HealthCare

\$11,000 - \$13,999

ARJ Infusion Services, Inc.

\$7,000 - \$10,999

MidWest Cornerstone Healthcare

\$3,000 - \$6,999

Medco - Hemophilia Health Services
Talecris Biotherapeutics
CSL Behring LLC
Caremark RX Inc.

\$1,000 - \$2,999

Axelacare
Walgreen/Option Care
Biomed Healthcare, Inc.
Grifols
Pinnacle Management Consulting
Accredo Health Inc
Brustkern, David N.

\$500 - \$999

Midland Information Resources

\$250 - \$499

ITA Group
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Lentz, Dr. Steven
Beate & Jerry Keith
Weidman, Dan & Peggy
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Wier, Peggy & Patrick
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Morrow, Terry & Debra
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From The Desk Of The HTC

Hemophilia & Bleeding Disorders Summer Camp Sponsors

By Karla Watkinson, RN

The Iowa Hemophilia and Thrombosis Center (HTC) was awarded a substantial grant in December 2009 by the University of Iowa Children's Hospital through the Children's Miracle Network to help support the Iowa Hemophilia & Bleeding Disorders camp, which was held June 20-25, 2010. The CMN grant was the largest gift the HTC has ever received to help support summer camp.

Along with the generous gift from the University of Iowa Children's Hospital and Children's Miracle Network, camp donations (or time) were also provided by Hemophilia of Iowa, Baxter, Bayer, ARJ, CSL Behring, Caremark, Wyeth-Pfizer, Novo Nordisk, Option Care, Bio Rx, Acreedo-HHS, Talecris, Grifols, Factor Health, AccurateRx, Mid-West Cornerstone, Penny and James Hauser, Stacie and Perry Cowen, Byron Stuart, Deb Melhado, Brian and Vicki Rodenburg, Nancy and John Golden, David Brustkern, Richard and Ethel Laughlin, Richard Faust, Jeff Beck, Ashish Sagrolikar, Jennifer Adams, Bill Laughlin, Derek Pagel, Diamond D. Logistics, Craig Ziegler, John and Claudia McCarthy, Robert Bellis, Arnola Siggelkow, Dan and Peggy Weidman, Craig Looney, Darrel and Carolyn Bell and family, Jerry and Beate Keith, Bill Watkinson, Jennifer M., Jennifer R., Sherri B., Kimberly J., Whitney Bullock, Katie Watkinson, and Dan Waldschmidt.

On behalf of the HTC and the children who participated in Hemophilia-Bleeding Disorders summer camp this year, we want to say a very heartfelt thank you to all of you! Without the generous support and donations, camp would not be possible. Thanks so much!

Bleeding Disorders
Legal Information Hotline
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Camp Tanager Timewarp Fantastic Time Traveling Adventure

By Karla Watkinson, RN

Hemophilia Bleeding Disorders summer camp began Sunday afternoon on June 20 and wrapped up on Friday, June 25. At camp this year, we traveled through time using the Blues Brothers', (Jake and Elwood), incredible time traveling machine! We saw Elvis, had Beach parties, found fossils and dinosaurs, and we were on the lookout for the evil Gargamel. We also learned important facts in the daily Camp Chronicle!

This year we had 48 campers, ages 6-17 years old; 30 were 11 and under while 18 campers were age 12 or older.

We had 15 first time campers this year; and, once again, minimal homesickness!!! The campers were awesome and a delight for the camp staff!

Some of our annual camp activities included: Sports & Games: Gaga ball, Volleyball, Basketball, Parachutes, Capture the Flag, Archery, Swimming, Dental Bingo, Art, Movies, Grilling out, Dancing, Karaoke, Photos and Autographs, final camp fire and talent show.

Our special camp activities for the week were:

- Woodworking: We used tools to build birdhouses.
- Bell's Family Farm: We enjoyed fishing, swimming, kayaking, eating, boating, gator rides, exploring the Conseville fire truck, and visiting with the entire Bell family and friends of the family. As usual, they fed us very well!!
- Training with Big Dog (Patrick Torrey): The program was for campers 12 and older; they worked on teambuilding, positive thinking and overcoming fears and increasing self-confidence and esteem. Ask your camper about their experiences and the activities they participated in. (From patricktorrey.com: *Pat Torrey is an internationally recognized facilitator and trainer known for his powerfully engaging programs that inspire kids, teachers and*

CEOs to believe in their own ability to function at their optimal level and challenge them to grow. Pat takes participants into new territory (both physically and emotionally) where they see their potential, enjoy taking risks and transfer these experiences back into their everyday life. His outrageously fun and invigorating programs feature challenge courses, team games and group interactions that give new meaning to the word 'teambuilding' and provide practical and inspiring tools for life. His genuine and inviting style blended with exceptional programs, enables him to meet people where they're at, allowing them to engage fully and to maximize their personal growth.)

- Fun City, Burlington, Iowa, field trip: A truly fun-filled day with go-karts, arcade, bowling, laser tag, simulators, 3-D rides and the indoor and outdoor water park. For lunch we had the largest pizzas I've ever seen--and they were great too!

- Infusion session and home therapy training occurred throughout the week at camp. We had a great time and several campers earned awards for participation and achievements!

- The Grand Finale, the Talent show... The stars were the campers who each were awarded individual certificates for their accomplishments, determination, persistence, and behavior shown throughout the week of camp. (Accomplishments range from leaving home for the first time, being a first time camper, getting along and working with others, home therapy infusion such as learning more about bleeding disorders, knowing what treatment product is used, signs and symptoms of bleeding, preparation and administration of factor, venipuncture-sticking someone else and then sticking themselves.)

Once again, camp was an amazing experience; and we have so many memories from the week! Tami and I are PROUD of each of you who participated!!!



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Dear Hemophilia of Iowa Members:

Are you interested in becoming a Board member of Hemophilia of Iowa? If you are a 2010 member of Hemophilia of Iowa, not working for a bleeding disorders company and willing to volunteer your time, we want to hear from YOU!!!

Hemophilia of Iowa currently has three (3) seats up for vote for consumers. The terms for these Board positions will go until the annual meeting in 2013. Board Member responsibility includes attending approximately 6 meetings annually in person (normally in the Des Moines/Iowa City area on Saturday or Sunday mornings). At times, there are Board of Director conference calls held in the evenings. Consumer Board members are reimbursed for mileage to and from meetings and events and will have the opportunity to help Hemophilia of Iowa better serve the bleeding disorders community in Iowa. Board members are also asked to actively participate in committees, which support events, fundraising and communication to the bleeding disorders community.

If you are interested in running for a seat on the Board, please send or e-mail a letter indicating your willingness to run for the Board of Directors, answer the following questions, and a photo of yourself (preferred but not mandatory). Please answer with a maximum of 2-3 sentences for each question.

- What is your relationship to the bleeding disorders community?
- What kind of experience/expertise would you have to bring to the chapter?
- Which of the chapter committees would you be most interested in helping with? (The chapter committees are listed below.)
- Anything else you would like to share about yourself and your desire about joining our Board.

If you have any questions about possibly becoming a new Board member, please contact Kari. Kari's contact information is listed below. Please send the above information to Kari Atkinson, PO Box 415, Central City, IA 52214, or via e-mail at hoi_president@yahoo.com. We ask that you have this in by September 1, 2010.

Active Committees are as follows: Membership, Advocacy, Annual Meeting, Family Education Day, Information, Camp Superfly, Bylaws, Fundraising, Scholarship and Golf.

Kari Atkinson
319-721-3964
hoi_president@yahoo.com

Oldest American with Inhibitor

(Continued from page 6)

Veterans' Administration hospital in charge of the procedure called in two dental surgeons, recalls Perry, and "ordered a lot of bags of cryoprecipitate to prepare for any complications." The surgery was a success.

In 1992 Perry began bleeding into his knee joints. For the first time, he received factor VIII concentrate, and his recovery was short and successful.

Perry underwent a laser surgical procedure in 2005 to remove part of his prostate. Following the procedure, to treat his severe bleeding, Perry was transferred to a different hospital where he received factor VIII concentrate. When the bleeding began to subside, Perry was sent home.

During his recovery, Perry began bleeding again. His local hospital didn't carry factor concentrates and was unfamiliar with hemophilia treatment, so Perry was transported to the hemophilia treatment center (HTC) at Munson Medical Center in northern Michigan. But this time, factor VIII concentrate didn't stop the bleeding. A Bethesda Inhibitor Assay confirmed the hematologists' suspicions: Perry had an inhibitor! His treatment was switched to a bypassing agent, a specialized clotting factor product used in patients with inhibitors. Perry's bleeding was finally under control, and he went home with a follow-up treatment plan and home nursing regimen.

Today, Perry keeps his bypassing agent at home, and calls a home nurse if he needs treatment. But the inhibitor doesn't slow him down much, even at his age. Perry credits his survival and quality of life to a positive attitude, healthy eating, exercise — and of course, factor. "I don't let anything get me down!" he says. "If I've got to go somewhere, I go. If I can't go, I don't go!"

Today, Perry lives on beautiful Drummond Island, Michigan. Betty has passed away, so he now lives alone. But he enjoys spending time on his computer, visiting casinos, going on cruises, and staying with his daughter in Phoenix.

Perry told me how fortunate he feels to have escaped viral transmissions, considering the amount cryoprecipitate and blood that he received during his early years of treatment. And he's grateful that although his daughters are carriers, none of his grandchildren has inherited hemophilia.

Thanks to the evolution of HTCs during Perry's long lifetime, and advanced treatments with bypassing agents, Perry may just be the oldest living person with an inhibitor — an amazing accomplishment for an inspiring man.

Kerry Fatula is executive director of the Western Pennsylvania chapter of National Hemophilia Foundation. She is also the mother of four boys, three with severe hemophilia A and inhibitors.

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Ask the Expert

By Mike Bradley
Vice President of Healthcare Economics and Reimbursement

Q: My health insurance company just assigned me a case manager. What does this person do, and how can we best work together?

Case managers are clinical specialists, usually nurses, employed by your insurance company to help coordinate your care. Often, case managers are assigned to all health plan enrollees with certain chronic health conditions. If your insurance company does not assign you a case manager, then you can ask for one.

Your case manager is your lifeline! He or she can help you navigate the forms, requirements, and documents regarding your benefits and coverage. The more your case manager knows about hemophilia, the more he or she can help you get the best coverage and care.

If your case manager doesn't know much about hemophilia, ask to change to someone with more experience. If no case manager has experience specifically with hemophilia, you can ask for someone who specializes in rare disorders.

You may have to educate your case manager. Your hemophilia treatment center (HTC) or specialty pharmacy

may have basic educational information on hemophilia that you can share.

Make sure your case manager has the names and phone numbers of your hematologist, HTC staff, and factor provider. If your case manager is unsure about an aspect of your care, such as your current treatment regimen, double check with your HTC or ask to speak with the case manager's supervisor. Remember, a case manager may misinterpret your care simply because he or she lacks experience with hemophilia.

Ask your case manager about the choices you can make concerning your treatment. For example, you may have a choice of factor distributors and factor concentrates. It's important to fully understand all your choices, and to strongly advocate for open access to all factor therapies and factor distributors.

When you are assigned a case manager, you can immediately start building a trusting relationship. Working together, make sure you understand your explanation of benefits (EOBs), which services or procedures need prior authorization, and your estimated costs. Your case manager can also help you track deductibles, annual limits, and lifetime cap amount, if your policy has one.

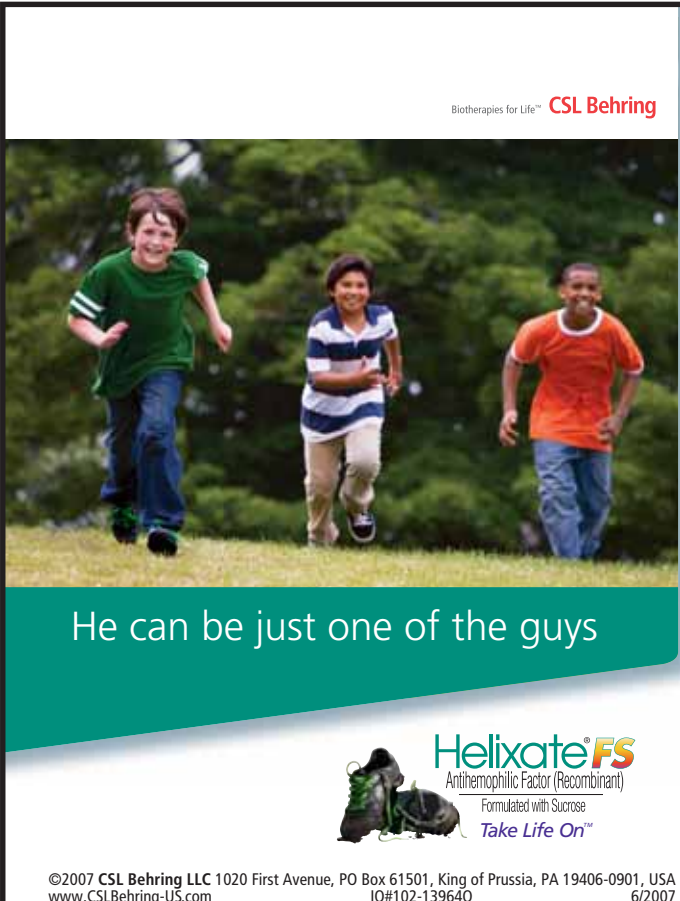
Start off on the right foot! Your case manager can be a great advocate for you and your child.

Q: I've heard a lot about a tier 4 pharmacy benefit. What is this, and how can it potentially impact my out-of-pocket costs for factor?

Private (commercial) insurance has two main forms of healthcare coverage: (1) the medical benefit covers costs such as inpatient hospital stays and laboratory and physician visits; (2) the pharmacy benefit covers most drugs. Factor can be covered under either the medical and pharmacy benefit, depending on your policy. Although the pharmacy benefit covers most drugs, you may be required to pay a certain amount, or co-payment, for your prescription when you pick it up. This amount depends on the pharmacy's contract with your employer or insurance company.

How much you pay out of pocket for that co-payment depends on how your insurance company classifies your drug. Under the pharmacy benefit, drug plans traditionally have been designed using tiers that group drugs by similar cost-sharing requirements, often a three-tier design with an increasing co-payment for each tier. Tier 1 drugs, usually generic drugs, normally have the lowest co-pays. Tier 2 drugs have a higher co-payment and are "preferred" brand-name drugs (often advertised on television). Tier 3 drugs

(Continued on page 15)



Biotherapies for Life™ CSL Behring

He can be just one of the guys

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American Red Cross Fined More Than \$16 Million for Blood Safety Violations

On June 17, 2010, the Food and Drug Administration (FDA) fined the American Red Cross (ARC) \$16.18 million for failure to address problems with the processing of blood products. ARC is the largest U.S. supplier of blood, plasma and other blood products with an average of four million donors.

The fine was issued after FDA inspections of a dozen ARC facilities conducted across the U.S. in 2008 and 2009. FDA inspectors found multiple examples of ARC's failure to correct shoddy practices related to the collection and manufacture of blood products. Some of the infractions

included mislabeled blood, failure to record complete donor information and potential air contamination.

ARC's noncompliance with federal laws and regulations compelled the FDA to take action. The fines were assessed under an amended 2003 consent decree--the original decree was in 1993--that outlines requirements for ARC to ensure safety of the nation's blood supply. According to the FDA, since 2003, ARC has made progress addressing some of its quality issues, including standardizing procedures, upgrading its National Testing Laboratories and increasing oversight. However, to be in

full compliance ARC needs to make "swift, additional progress" on all of the issues outlined by the FDA.

"The FDA is hopeful these fines will encourage the Red Cross to act more quickly to take the actions necessary to address and correct the issues that have contributed to these violations," explained the agency.

"Despite the compliance failures, FDA found no evidence that the Red Cross violations endangered any patients and the blood supply is believed to be safe. Multiple layers of safeguards are in place to protect and enhance the safety of blood products. However, these types of violations decrease the assurance that blood products manufactured by American Red Cross will continue to be safe and have the potential to compromise the safety of the blood supply," said the FDA in its statement.

Since 2003, the FDA has fined ARC \$21 million, excluding the June 17, 2010 fine.

Source: The Los Angeles Times (online), June 18, 2010, Reuters (online), June 18, 2010

How Does Hepatitis C Transmission Occur?

Hepatitis C transmission occurs mostly through infected blood and blood products. Before 1990, there was no way to test for the virus when people donated blood. So some people were infected when they had a blood transfusion. But because we can now test donated blood before it's used, it is extremely rare for people to get hepatitis C from blood transfusions.

Today, transmission of hepatitis C occurs most frequently through infected blood, whether it is from working in a laboratory or a dialysis unit, by infected needles used for tattoos or body piercings, or through sharing drug needles. In a few cases, people have been infected with hepatitis C by sharing objects that may have a tiny amount of blood on them, such as a toothbrush, razor, or tools used for manicures.

Hepatitis C can also be spread by sexual intercourse, but this is rare. For steady sexual partners, there are not any recommendations about changing your sexual practices just because you or your partner has hepatitis C. But having more than one sex partner does increase your chance of getting the virus.

Can Transmission of Hepatitis C Occur Through Normal Activities?

Hepatitis C is not transmitted through normal, everyday activities. You won't get infected from things like:

- Sitting next to a person with the

virus

- Shaking hands
- Hugging
- Kissing
- Sharing eating utensils.

Though we know most methods of hepatitis C transmission, some people are never able to figure out exactly how they got the infection.

How Can I Avoid Transmitting Hepatitis C?

There are some things you can do to avoid spreading **hepatitis C** if you are already infected. You should not:

- Donate blood
- Take any illegal drugs
- Share any types of needles

Remember, hepatitis C is most commonly spread through infected blood.

Don't let other people borrow your razor, toothbrush, or anything else that might have blood on it.

If you are in a monogamous relationship, you should talk with your healthcare provider about the risk of passing the virus to your partner through sex. You should also consider having your partner tested for the **hepatitis C virus**. If you have more than one sex partner, you or your partners should always use condoms when you have sex.

These suggestions can help stop hepatitis C transmission.

Source: <http://hepatitis-c.emedtv.com>

5 PROACTIVE CAREER TIPS

- Write a professional resume and cover letter.
- Search for jobs.
- Network and utilize personal contacts.
- Consult a vocational rehabilitation counselor.
- Ace the interview.

Source: Taken in part from CARE, Educational Series, Vol. 3, Baxter

Hemophilia of Iowa does not endorse any specific industry organization, product or service, or offer any advice regarding the patronization or use of any specific industry organization, product or service.

New Educational Resource for Adults with Hemophilia

More people with hemophilia are entering middle and older age than ever before. They are beginning to face age-related health issues that were not as common within the hemophilia community in the past.

To help adults address these unique and emerging needs, Baxter has created a new resource, *Perspectives*. *Perspectives* provides insight into opportunities and challenges that are relevant to adults, featuring members of the community who share their personal stories.

The first two topics covered by *Perspectives* are heart health and fitness. Below are brief summaries of the comprehensive and valuable information written to address the needs of the adult hemophilia community.

Heart Health and Hemophilia: A New Challenge

In the past, some researchers thought that the deficiency of factor VIII in hemophilia might actually protect people from cardiovascular disease. However, studies have not been able to confirm this. This health guide identifies the lifestyle habits and risk factors that adults with hemophilia should be aware of to help maintain a healthy heart.

One section pertains directly to people with hemophilia and HIV who are treated with highly active antiretroviral therapy (HAART).

For people with hemophilia who do suffer a cardiovascular event, invasive treatments can be more risky, so heart disease prevention is extremely important. While there are no specific guidelines for preventing cardiovascular disease in people with hemophilia, the booklet recommends adults should approach prevention in the same way as people without it – by addressing modifiable risk factors through lifestyle changes, such as quitting smoking, eating healthy and controlling their weight. The booklet also highlights the American Heart Association's recommendation that cardiovascular screening begin at age 20.

In *Heart Health and Hemophilia*, 47-year-old Ron shared his personal experiences with an irregular heartbeat and unusually dangerous increases in his blood pressure. Upon arriving at his local hospital, Ron told the emergency room staff that he had hemophilia, yet they treated him like they would anyone else. "They even wanted to give me blood thinners," Ron remembered. He started looking for a doctor with whom he'd be comfortable while keeping an eye on his blood pressure and heart rate.

Some people with hemophilia become sedentary and overweight because of their joint damage. As *Perspectives* reminds us, obesity and a lack of physical activity are both major risk factors for heart disease, so it's important to stay as active as possible.

Sports & Exercise: The Right Balance

Perspectives' second health guide points out that avoiding heart disease is but one reason to engage in physical activities. While many adults with hemophilia are concerned about injuries or bleeds, regular exercise has a long list of benefits important to the community, including promoting muscle strength, bone and joint health, and proper body weight.

The findings of the "Hemophilia and Exercise Project" showed that after two years of appropriate sports training, participants' activity level increased significantly and their knee pain decreased significantly, without more joint damage, more frequent bleeds, or more factor use.

Choose Wisely

Adults with hemophilia should choose activities that put low impact on joints but still increase muscle strength and flexibility. The booklet encourages readers to talk with their doctors or HTC staff about the appropriateness of each activity and what precautions might be necessary. It also suggests discussing with the HTC how to best coordinate exercise and hemophilia therapy. People who plan to use a trainer or physical therapist for instruction and support should try to find one who has experience with hemophilia. In any case, letting a trainer know about one's condition and working together to tailor a program to the person's specific physical needs and ability is a key to success.

This health guide also provides descriptions and illustrations of strength, flexibility and conditioning programs that are helpful regardless of a reader's level of training in personal fitness.

To request a copy of these and future editions of *Perspectives*, contact your Hemophilia Treatment Center (HTC).

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The Teething Infant

By Karla Watkinson, RN

It seems we have recently had quite a few questions about teething and what can be done to sooth those inflamed and painful gums in infants. Along with the basic teething rings, cold and wet washcloths, Tylenol, and Oral Gel, we weren't sure what to offer. Therefore, we contacted Pediatric Dentistry and spoke to Gayle Gilbaugh and Dr. Burke.

Pediatric Dentistry does not recommend Oral Gel unless Tylenol does not work, and it is absolutely necessary. The reason for this is that most often the infant swallows the gel before it has a chance to be absorbed by the gum line; potentially numbing the throat, which may cause choking and difficulty swallowing, thus, increasing the risk of aspiration (food or liquid getting into the lungs).

The New Parent Guide recommends the same methods of relief as mentioned above and the use of cold foods and drinks as well as using the parent's fingers to put pressure on

the area (called counter pressure). For more information from the New Parent Guide, you can visit: <http://www.thenewparentsguide.com/baby-teething.htm>.

Another device, new to me, is the Munchkin Fresh Food Feeder or Sassy Teething Feeder. It is ideal to put frozen foods in such as bananas or pureed fruit or vegetables. It can then be given and used for the infant to "munch" on while

applying cold pressure. An added bonus is that it is a nutritional snack as well!

(From the Sassy Teething Feeder: Convenient storage cap. Water-filled area inside handle keeps food chilled. Keep it cool! Easy grip handle. Childproof lock. Great for fruit & veggies! Perfect for home or travel, the Teething Feeder is a great way to give your baby whole, fresh, age appropriate foods, while reducing the risk of choking. The unique chill feature in the Teething Feeder handle and the convenient storage cap help keep foods fresh while traveling with baby.)



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Octapharma USA Announces FDA Approval of wilate® - the First Replacement Therapy Developed Specifically for von Willebrand Disease

Octapharma USA announces the U.S. Food and Drug Administration has approved wilate® for the treatment of spontaneous and trauma-induced bleeding episodes in patients with all types of von Willebrand disease (VWD). Wilate® is a newly developed, high-purity, double virus inactivated von Willebrand Factor/Coagulation Factor VIII Concentrate (Human) that demonstrated efficacy for all types of VWD including pediatric patients in four prospective clinical trials utilizing both objective and subjective criteria.

Wilate® is indicated for the treatment of spontaneous and trauma-induced bleeding episodes in patients with severe VWD as well as patients with mild or moderate VWD in whom the use of desmopressin is known or suspected to be ineffective or contraindicated.⁽¹⁾ Wilate® is the first double virus inactivated VWF/FVIII (von Willebrand Factor / Factor FVIII), high-purity concentrate, utilizing the solvent/detergent (S/D) process and a special terminal dry-heating (TDH) system. The selected purification processes isolates the VWF/FVIII complex under highly protein-protecting conditions, resulting in a 1:1 ratio of VWF:RCo (ristocetin cofactor) and FVIII activities that is similar to normal plasma. No albumin is added as a stabilizer. Wilate® is exclusively derived from large pools of human plasma collected in U.S. FDA approved plasma donation centers.

Baxter Introduces 1700 IU Intermediate Potency for ADVATE therapy

Baxter has added a 1700IU (international unit) intermediate potency vial size to its selection of dosage strengths for ADVATE [Antihemophilic Factor (Recombinant), Plasma/Albumin-Free Method].

“Regardless of the brand used, infusing a single vial can help simplify how a person with hemophilia manages his therapy, or how a parent infuses his son with fewer steps and less worry,” said Dr. Bruce Ewenstein, Vice President of Clinical Affairs, Baxter Healthcare. “Single-vial dosing can mean fewer boxes to store at home and fewer supplies to bring while traveling. For a teen, a single vial can help encourage his independence and his parents’ confidence that he will continue to infuse as his doctor prescribes. The infusion process can be as little as 90 seconds with a single vial*. That is a small amount of time compared to having to infuse with multiple vials.”

Baxter and ADVATE are registered trademarks of Baxter International Inc.

ADVATE is not used to treat von Willebrand disease.

Ask the Expert

(Continued from page 11)

are assigned the highest co-payment. These are “non-preferred” brand-name drugs, more expensive drugs, or drugs lacking proof of greater effectiveness. Some health plans have added a fourth tier for specialty or biologically derived drugs, such as factor.

Some health insurers have created a special pricing category for specialty drugs. On a fourth tier, consumers are charged either an increased co-payment or a percentage of the actual cost of the drug. Fourth tiers can require you to pay 25% to 35% of the drug price.*

Currently, factor is typically covered under the medical benefit and will not be impacted by this new tier 4 category. But increasingly, private insurance plans are shifting factor to the pharmacy benefit or creating a new specialty drug benefit that uses tiered co-payments.

It’s essential to monitor where in your health insurance factor is covered. Your insurance company may change this benefit at any time and should inform you of any planned changes.

*Walsh, Bill. “The Tier 4 Phenomenon: Shifting the High Cost of Drugs to Consumers.” AARP Intelligence and Briefing Report. March 2009. www.aarp.org/research/health/drugs/tierfour
Source: LA Kelley Communications, 2009. www.kelleycom.com.



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It's Not About Fashion: The Essential Medical IDs

By Kevin Correa

If you suffer from an injury or illness and are unable to tell medical professionals that you have hemophilia, medical IDs will do it for you.

Medical IDs come in many forms, most commonly bracelets and pendants. For people with hemophilia, IDs are inscribed with the phone number of your emergency contact or hemophilia treatment center (HTC), and your factor deficiency. Subscription services link your medical ID to a 24/7 call center, which can access your medical records, helping ensure that you receive appropriate treatment. And many hemophilia foundations provide assistance to pay the membership fee.

Sounds great, right? Then why do so many young people with hemophilia go without a medical ID?

What's with the Bracelet?

The most common reason is the obvious one — it attracts unwanted questions.

“Adolescents don't like to feel different, and a medical ID is pretty obvious,” says Ellen Kachalsky, a social worker at Henry Ford Hospital's Adult HTC. “When teens first transfer into our adult practice, only about half of them are wearing medical IDs.”

“I never wanted to draw attention to myself,” recalls Michael, 44, who has severe hemophilia. “The bracelet was so obvious. I just didn't want to answer all the questions.”

Craig, who also has hemophilia, agrees. “I never wore mine as a kid. I was too ashamed to wear it, and I didn't want kids to see it.”

Hiding Hemophilia beyond the Teenage Years

It isn't just transitioning teens and young men who choose not to wear their medical IDs.

“Many of my adult [hemophilia] patients — both men and women — don't wear them,” says Dr. Danielle Nance, a hemostasis and thrombosis specialist. “They all have at least one or two necklaces or bracelets hanging around, but they never wear them to clinic.”

Like Dr. Nance's patients, Michael had various bracelets and pendants, but didn't wear anything routinely until his mid-thirties.

The catalyst for Michael was his family.

“I finally realized it's not just about me. I have a family, and thought, ‘What if something happened to me and I wasn't wearing my bracelet?’”

Craig echoes this. “It was not until I was engaged to be married that I realized that I should wear the necklace. Looking back, I really should have

been wearing it the whole time for my parents' sake, to ease their fears.” While medical IDs can certainly give loved ones some peace of mind, don't lose sight of the fact that you wear it for your own protection.

Naked Without It

Even people who don't wear their medical IDs won't deny their value. So how can transitioning teens and young adults be convinced to wear one?

One way is to get them into the habit. Kachalsky informs her new patients of the HTC's expectation that they will wear some form of medical ID. “We hope that they will get used to wearing a medical ID and feel naked without it,” she explains. About half of her patients who did not routinely wear medical IDs when they first enrolled at the HTC do eventually wear them.

But persuasion goes beyond the jewelry's medical benefit. At the root is being comfortable with your hemophilia. The more comfortable you are, the more likely you will be to wear something that draws attention to it.

This was true with Michael. “I started wearing my bracelet when I'd gotten to a point in my life where I was more comfortable with myself and my health issues,” he says insightfully.

A Decision with Consequences

Choosing to wear a medical ID or to carry an ICE (in case of emergency) card can be literally a life-or-death decision. “As a responder, it's critical to get the entire picture of a person's health condition at an emergency scene,” emphasizes Albert Beardsley, a Massachusetts fire chief. “The first thing we look for — especially if there isn't a friend or next of kin available — is the medical ID or wallet ID card.”

Beardsley adds, “If we see an alert bracelet, we can update responding paramedics. An important part of our protocols is to alert the next level of care what we have coming into their facility. In many instances this will give the emergency

room advanced notice to have specialists in the ER upon the ambulance's arrival.”

Recently a doctor was preparing to perform a colonoscopy on a hemophilic man who spoke only Spanish. The man assumed that the doctor had all of his medical information. Just before the procedure, the doctor noticed the medical ID bracelet, called the man's HTC, and postponed the procedure until they had factor on hand in case they needed to perform biopsies.

And what if you're *not* wearing it? At age 16, “James” wasn't wearing a medical ID when he was brutally assaulted in the company of a friend. When the ambulance arrived, James wasn't able to communicate clearly with paramedics, he had no medical ID, and his friend knew only that James had hemophilia. Finally, at the hospital, staff learned that James had severe hemophilia and an inhibitor, so he was transferred to his HTC for appropriate treatment. His condition was so critical that doctors wanted to use an air ambulance for transport, but the helicopter was in use, so they were forced to make the trip via highways, seriously delaying treatment.

James, now 34, knows that his treatment would have been different had he been wearing a medical ID. “I'm almost positive that if I had the medical card I carry now and the medical alert necklace I wear, I would have gone straight to [my HTC] and they would have had factor ready and waiting.”

“The medic alert tag is there to save time,” explains Dr. Nance. “And for people who are bleeding, a few minutes' heads-up for the doctor can mean the difference between getting factor first and getting factor eight hours later.”

Patients with bleeding disorders are very rare. Even experienced physicians may not know exactly how to treat them. With a medical ID, that knowledge is an easy phone call away.”

Get Past Your Hangups

The bleeding disorder community faces a tough challenge in convincing everyone to wear a medical ID. Ironically, the toughest converts will be young adults in their “invincible” years, who are most likely to need a medical ID but least likely to wear it.

To make medical IDs more appealing,

(Continued on page 17)

An Evening to Remember, Recognize, and Reform...

“**Bad Blood: A Cautionary Tale**”, directed by Marilyn Ness, a documentary ten years in the making, will premiere July 2010 in New York City as the launch of a multi-city theatrical screening series co-hosted by a coalition of national gay rights and hemophilia advocacy groups including Gay Men’s Health Crisis (GMHC), Committee of Ten Thousand (COTT), Hemophilia Federation of America (HFA), National Hemophilia Foundation (NHF), and World Federation of Hemophilia (WFH). The film documents the tragic history and facts surrounding the discovery of HIV in the U.S. blood supply in the early days of the AIDS epidemic...

...Filmmaker Marilyn Ness explains, “Each of us owes the hemophilia community a debt of gratitude for their unintended and tragic role in alerting the country to the contamination of the U.S. blood supply with HIV and hepatitis from the 1970s through the 1990s. Since then, the bleeding disorders groups stand as guardians of the nation’s blood supply and are now joined in their advocacy efforts by Gay Men’s Health Crisis. I am tremendously gratified that ‘Bad Blood’ has united these two groups to work together toward blood safety and FDA reform on behalf of all Americans. I can think of no more fitting a memorial for those who were unnecessarily lost than to continue their work ensuring history will never again be repeated.”

Through the eyes of survivors and family members, the documentary film “Bad Blood” chronicles how a miracle

treatment for hemophilia became an agent of death for 10,000 Americans. Faced with evidence that pharmaceutical companies and government regulators knew the medicine was contaminated with deadly viruses, they launched a powerful and inspiring fight to right the system that failed them and to make it safer for all. The film brings together patients, doctors, drug manufacturers, and government regulators to recollect how the worst medical disaster of the 20th Century was allowed to occur and cautions us to remember, remain vigilant, and to demand a safer system...

...Both gay men and people with hemophilia have been disproportionately impacted by the HIV epidemic. In the early 1980s, as HIV breached the nation’s blood supply, nearly 90% of Americans with severe hemophilia, a rare bleeding disorder, became either infected or co-infected with HIV and hepatitis from contaminated blood-based medications; more than 50% have since died. Critical advancements in HIV prevention, treatment, and research can be linked directly to the years of successful advocacy by both the bleeding disorders and gay rights communities.

The DVD of “Bad Blood: A Cautionary Tale” will be on sale for educational and institutional use beginning July 29th, 2010 and to the public on **December 1, 2010** marking World AIDS Day. For more info, please visit www.BadBloodDocumentary.com...

Source: NHF website, July 2010 eNotes.
(This is a partial reprint of the eNotes)

The Essential Medical IDs

(Continued from page 16)

manufacturers constantly update their products with new styles. Styles range from the traditional to black leather to more customizable and discreet options, including watches from designers like Citizen. You can also find medical sports bands, dog tags, and other styles that teens and young adults don’t mind wearing.

At the end of the day, your medical ID is not a fashion statement. It’s an essential part of your hemophilia treatment plan.

Men like Michael, Craig and James can have a huge impact on younger people in the community. They’ve been through the pressures of the young adult years. They know what it’s like when people ask the unwelcome, awkward questions.

To the young people not wearing their medical IDs, Michael says, “You have to get past your hangups and vanity. A bracelet is all you really have as a backup if you get hurt and can’t talk.”

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Mayo Clinic Examines Circumcision-Induced Bleeding

In March, researchers at the Mayo Clinic (MC) in Rochester, MN, published a retrospective study of circumcision in patients with bleeding disorders. The purpose of the study was to examine the outcomes of circumcisions performed on patients who were evaluated at MC to determine the extent of related complications and develop guidelines for clinical management. The lead author of the study was Vilmarie Rodriguez, MD, Division of Pediatric Hematology and Oncology at MC.

Investigators looked at the records of 48 children and young adults who had been circumcised from 2000-2007. They ranged from 11 months to 21 years old, with an average age of 15.

Of these, 21 had a known bleeding disorder at the time of circumcision: 15 had hemophilia A, 2 had hemophilia B and 4 had von Willebrand disease. Twelve of the 21 patients were treated with factor products prior to the procedure; three experienced bleeding complications.

The remaining 27 patients were diagnosed with bleeding disorders later in life. Among them, eight experienced bleeding complications. The overall incidence of bleeding post-circumcision was 11/48 patients, or 23%. The results led investigators to report that this incidence rate in bleeding disorder patients is “comparable” to that reported for unaffected children. They also reported that some patients

still experienced significant bleeding despite what was considered adequate factor therapy given before and after circumcision.

“Risks and benefits should be discussed with parents before the procedure, and it should be stressed that bleeding can still occur despite adequate factor replacement. The patient should be observed in the hospital during and after the circumcision procedure to allow prompt intervention if bleeding occurs,” concluded the authors.

The study, “To Circumcise or Not to Circumcise? Circumcision in Patients with Bleeding Disorders,” was published in the March 2010 issue of *Haemophilia*.

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Swedish Study Assesses Osteoporosis Prevention in People with Severe Hemophilia

In May researchers in Sweden published the results of a study analyzing whether physical activity, accompanied by a long-term prophylactic (preventive) treatment regimen, is a significant determining factor in the prevention of osteoporosis in patients with severe hemophilia. The lead investigator of the study was Mohamed Mansour Khawaji, Malmö University Hospital, Lund University.

Osteoporosis is characterized by loss of bone mass and degeneration of bone tissue. Left untreated, bones become fragile and are prone to fractures, especially in the hip, spine, neck and wrist. A bone mineral density (BMD) test helps determine whether a patient has osteoporosis. Physical activity, particularly weight-bearing

exercise, is one of the key contributors to maintaining and enhancing bone strength.

Of the 30 patients (28 with hemophilia A, 2 with hemophilia B), all received regular long-term prophylaxis (2-3 factor infusions per week) for an average of 29.5 years. The majority (25) started the regimen in early childhood (average age was 2 years), five began prophylaxis in late childhood and adolescence (ranging from 7-15 years old). An enhanced BMD test was conducted in each patient.

Physical activity was assessed through a “Modifiable Activity Questionnaire,” a self-reporting tool used on leisure and occupational activities for the previous 12 months. Nearly all participants reported engaging in weight-bearing

activities (96.6%). Seventeen (56.6%) participated in “vigorous activities” such as wood chopping and jogging, while 18 (60%) engaged in nonweight-bearing activities, including cycling and swimming. Walking was also a commonly cited activity (63.3%).

“In conclusion, with adequate long-term prophylaxis, patients with hemophilia are maintaining bone mass, whereas the level of physical activity in terms of intensity and duration play a minor role. In addition, these results may support the proposition that the responsiveness to either an increase or a decrease in mechanical strain is probably more important for bone mass in children and adolescents rather than in adults and also supports the importance of starting prophylaxis early in life so that the children can lead active life and normal bone density when they grow up,” reported the authors.

The study, “Physical Activity for Prevention of Osteoporosis in Patients with Severe haemophilia on Long-term Prophylaxis,” was published in the May 2010 issue of *Haemophilia*.

Researchers Measure Satisfaction with Global Endometrial Ablation in Women with Bleeding Disorders

In an April 2010 study, researchers at the Mayo Clinic examined health-related quality of life (HRQoL) and satisfaction of women with bleeding disorders who had undergone global endometrial ablation (GEA) for excessive menstrual bleeding. The lead investigator of the study was Sherif A. El-Nashar, MBBCh, Department of Obstetrics and Gynecology, Mayo Clinic, Rochester, MN.

El-Nashar and his colleagues surveyed 36 women with bleeding disorders and 110 patients without bleeding disorders, all of whom had undergone GEA for heavy menstrual bleeding, or menorrhagia. During the procedure, the uterine lining is destroyed, leaving the uterus intact. Once scar tissue forms, the menstrual flow decreases as does pain. In all, 96 women responded (66%).

Results showed an improved HRQoL

and high satisfaction were reported by both groups (95% for women with bleeding disorders and 84% for those without).

“The current report provides additional supportive data about the long-term, patient reported outcome after GEA. The best available evidence supports the use of GEA as a minimally invasive, safe, and effective therapeutic option for women with acquired or congenital bleeding disorders who have acute or chronic menorrhagia,” concluded the authors.

The study, “Health-Related Quality of Life and Patient Satisfaction After Global Endometrial Ablation for Menorrhagia in Women with Bleeding Disorders: A Follow-up Survey and Systematic Review,” was published in the April 2010 issue of the *American Journal of Obstetrics & Gynecology*.

Source: HealthDay News, May 5, 2010

A SPECIAL THANK YOU

By Karla Watkinson, RN

The HTC nurses want to send a special thanks to the nurses who volunteered their time and expertise to help us with home therapy education and infusion sessions! If we had not had the extra hands, Tami and I would not have been able accomplish the goals we had for the campers (and we’d still be doing M-W-F treatments)! Thank you to Jennifer, Jennifer, Kimberly, and Sherri—you made our experience less stressful! Also thanks to CAMP TANAGER and the AWESOME staff; you are amazing!

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AND FINALLY . . .

I hope you are having a great summer! It is hard to believe that school will be starting shortly after you receive this issue of the BloodLine. For those of you going off to college, it is a wonderful and exciting time. I know from the parent's perspective that we want our children to succeed and fly from the nest. I also know that turning and leaving each one of my children at their new residence for the first time was one of the most difficult things I have ever done. And, even though I am not a "crier" by nature, I have to admit that I shed quite a few tears on the way home. I also know that the stress level dropped in my life after our son moved out--I was no longer there to see or hear about different bleeding episodes. On the other hand, when I did hear about a headache or joint injury, my stress level jumped right up there for the very same reason--I was unable to see it with my own eyes so my imagination furnished every possible scenario. Yet, our son survived and thrived and, ironically, so did his dad and I. So, take heart, your kids will have so many new experiences that you are not going to know about (probably a good thing for quite a few of them...) and yet they will still share their lives with you. It will just be on a different level and can be just as interesting if you are willing to step back and let them take the initiative in sharing with you. Enjoy this new phase of your life!



The medical information contained in this newsletter is for information purposes only and is not to be taken as medical advice. If you have any questions or concerns, always, check with your healthcare provider.